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Report of the Washington Group on Disability Statistics

Note by the Secretary-General

In accordance with a request of the Statistical Commission at its thirty-fifth session,** the Secretary-General has the honour to transmit to the Statistical Commission the report of the Washington Group on Disability Statistics (secretariat: National Center for Health Statistics, United States of America). The report is submitted to the Statistical Commission for information.

* E/CN.3/2005/1.

** See *Official Records of the Economic and Social Council, 2004, Supplement No. 4* (E/2004/24), chap. I.A.

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Report of the Washington Group on Disability Statistics

Purpose

1. The main purpose of the Washington Group on Disability Statistics is the promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys which will provide basic necessary information on disability throughout the world. More specifically, the Washington Group aims to guide the development of a small set or sets of general disability measures, suitable for use in censuses, sample-based national surveys, or other statistical formats, for the primary purpose of informing policy on equalization of opportunities. The second priority of the Washington Group is to recommend one or more extended sets of survey items to measure disability, or principles for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items are intended to be related to the general measure(s). The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) has been accepted as the basic framework for the development of the sets.

2. All disability measures recommended by the group, general or extended, will be accompanied by descriptions of their technical properties and methodological guidance will be given on their implementation and their applicability to all sections of the population. The Washington Group will disseminate work products globally through the World Wide Web.

Participants

3. Representatives of national statistical offices, international organizations and non-governmental organizations participated in the last four meetings.

4. Current country representatives include Australia, Austria, Belgium, Brazil, Canada, Columbia, the Czech Republic, Denmark, Egypt, Estonia, Finland, France, Greece, Hong Kong (China), Hungary, India, Ireland, Israel, Italy, Latvia, Macao (China), New Zealand, the Netherlands, Norway, Palestine, Peru, the Philippines, Poland, Romania, Sierra Leone, Slovenia, South Africa, Spain, St. Lucia, Sweden, Turkey, Uganda, the United Kingdom of Great Britain and Northern Ireland, and the United States of America.

5. Current international and non-governmental organizations include the European Disability Forum, Eurostat, the International Federation for Spina Bifida and Hydrocephalus, the International Development Project, the International Labour Organization (ILO), the Organization for Economic Cooperation and Development Health Policy Unit, the Partnership Health, Eurostat, Rehabilitation International, the United Nations Statistics Division, the Economic Commission for Europe, the Economic and Social Commission for Asia and the Pacific (ESCAP), the Economic and Social Commission for Western Asia, the World Bank and WHO.

Past meetings/major outcomes

First meeting: Washington, D.C., 18-20 February 2002

6. It was agreed that: (a) it is important and possible to craft internationally comparable general disability measures; (b) short and long set(s) of measures that are interrelated are needed; (c) the ICF model will be used as a framework in developing disability measures; and (d) census questions are the first priority. Finally, next steps were established.

Second meeting: Ottawa, 9-10 January 2003

7. A link was established between the purpose(s) of a general disability measure and aspects of measurement. A conceptual matrix was developed linking the purpose of a general disability measure with conceptual definitions and question characteristics. An empirical matrix was developed evaluating the characteristics of general measures currently in use according to the dimensions of the conceptual matrix. Both matrices helped the Washington Group to identify gaps in disability measurement.

Third meeting: Brussels, 19-20 February 2004

8. It was agreed that disability is multidimensional, thus we cannot ascertain the single "true" disabled population. Different purposes are related to different dimensions of disability or different conceptual components of disability models. A position paper outlining major classes of purposes of an internationally comparable general disability measure and prioritizing the purpose of equalization of opportunities was discussed by the Group. Equalization of opportunities was agreed upon and selected as the purpose for development of an internationally comparable general disability measure. A set of appendices accompanied the paper. The first provided ICF terms and definitions of the relative ICF concepts; the second provided guidelines for translating those concepts into survey measurement items. A working group was designated to generate a draft set of questions related to this purpose. In addition, two other working groups were formed to propose methods for implementing the general disability measure and to propose an approach for developing extended measurement sets related to it. Finally, a plan for Washington Group governance was adopted.

Products

9. Proceedings (presentations and papers) from the first three meetings, reports to the United Nations Statistical Commission, final meeting reports and information on upcoming meetings can be accessed through the Washington Group web site, currently hosted by the National Center for Health Statistics, United States of America (http://www.cdc.gov/nchs/citygroup.htm).

Report of the 2004 meeting

10. The fourth meeting of the Washington Group on Disability Statistics was held in Bangkok from 29 September to 1 October 2004 and hosted by ESCAP and the Thai National Statistical Office. The meeting was attended by 40 persons representing 23 countries (Africa, Asia, Europe, the Middle East, North America, the Pacific, South America) and five international organizations (the United Nations

and its affiliates, the World Bank, ILO, WHO, Rehabilitation International). The meeting was organized in seven sessions comprised of presentations of draft position papers followed by focused discussion addressing specific session objectives. Session outcomes included key agreements, products and a work plan. Objectives for the fourth meeting were to:

(a) Present work on development of the general disability measure (working group 1);

(b) Discuss the proposed plan for implementing the general disability measure (working group 2);

(c) Discuss the proposed approach for development of extended measurement sets (working group 3);

(d) Discuss methodological issues related to full population coverage;

(e) Discuss strategic issues.

11. There were several key outcomes of the meeting. First, a draft set of questions for the general disability measure was agreed upon conceptually, but wording revisions were required prior to pretesting. Working group 1 (on the general measure) would revise wording of the proposed questions with input from Washington Group members and decide on the final questions, including clarification of revisions made, by December 2004. The question set would undergo cognitive testing and pretesting. Issues requiring testing were delineated. Questions based on six domains at the borderline of the ICF components of body functions/impairments and activities/limitations would be pretested as potential candidates for inclusion; four domains were considered the core (walking, seeing, hearing, and cognition), but two additional domains would also be examined (self-care and communication). A severity scale would be used in the response categories.

12. A new working group (on implementation) was formed to develop six protocols necessary to implement the general disability measure effectively. The protocols included: (a) establishing objectives and an evaluation plan for cognitive and pilot testing; (b) establishing plans for report writing, including tabulation and analysis; (c) establishing plans for cognitive testing; (d) translation; (e) enumerator training; and (f) sample design issues (such as the number of households to be covered and identification of other census questions to be included with the disability questions on the pilot test). Existing protocols, such as the United Nations guidelines and the European Union translation protocol would be used as references. The protocols were to be completed in a four month time frame. Countries willing to participate in pretesting were identified. In view of the comprehensive work involved in the development of those protocols and the strict deadlines, the working group proposed that the group should work in conjunction with a consultant.

13. Working group 3 (on extended measurement sets) would initiate development of the first two extended sets of measures on disability. It was agreed that the purpose of the extended measurement sets was assessment of equalization of opportunities. The extended sets were intended as modules that would go into other existing national surveys. The working group would develop one extended set of questions expanding on the six domains identified for the short general measure (more detail) and adding questions on domains that reflected other basic activities. A second extended set would be developed encompassing more complex

activities/limitations, participation/restrictions and environmental factors. The justification for the extended sets would be specified. The working group would also identify indicators that would be used to demonstrate equalization of opportunities. For the following meeting, members of the working group would develop a paper examining the domains of participation and environment and how they related to existing questionnaires in population-wide surveys.

14. The Washington Group agreed that the issue of persons excluded from national surveys was important and that differences in subpopulations that were excluded from national surveys across countries might affect the comparability of disability measures. A new working group on methodological issues was formed to address the topic of full population coverage as well as other methodological issues, including the effects of proxy and non-response, the effects of questionnaire administration mode and the potential for harmonization of health and disability data using modern calibration techniques. Additional questions would be included in the following country report to identify groups excluded from national surveys. At the following meeting, the working group would examine whether it was feasible to include those subpopulations and whether the proposed questions on disability were relevant for those populations.

15. The United Nations Statistics Division would work on analysing the Washington Group country reports to better understand disparate prevalence estimates on disability. It would report on that work at the fifth Washington Group meeting. The fifth Washington Group meeting would be held in Rio de Janeiro, Brazil, from 21 to 23 September 2005. Objectives for the fifth Washington Group meeting were to:

(a) Present work on continued development of the general disability measure, including revisions based on the results of cognitive and pretesting (working group on the general measure);

(b) Present work on the written protocols and plan for implementing the general disability measure, including lessons learned from pretesting (working group on implementation);

(c) Present work on the development of the extended measurement set and the associated paper on its relationship to participation and the environment (working group on extended measures);

(d) Discuss methodological issues related to proxy and non-response and continue discussion of full population coverage (working group on methodological issues);

(e) Discuss strategic issues.

16. In keeping with the United Nations guidelines, issues of gender bias and other potential sources of bias would be a consideration of all Washington Group work. Executive summaries of the past three meetings were posted on the Washington Group web site (http://www.cdc.gov/nchs/citygroup.htm) together with presentations and papers from the meetings.